

**Virginia Genetics Advisory Committee  
Tuesday, October 3, 2006  
10:00 a.m. – 12:00 Noon**

**Division of Consolidated Laboratory Services  
Training Room T-23  
600 North 5th Street  
Richmond, VA 23219  
Telephone (804) 648-4480**

**MINUTES**

**Present:** Audrey Greene, RN-VDH; Charlie Stevenson, MS—DCLS; Joann Bodurtha, MD, MPH, Chair-VCU; Kathy Odum, RN—VDH; Laura Duncan, MPH, RD, VCU; Lynette Bartlett, RN—VDH; Melody Yeargin—CHKD; Nancy Bullock, RN, MPH—VDH; Nancy Ford, MPH, RN—VDH; Rafael Randolph—VDH; Sara Long—MOD; Sarah Elsea, PhD, FACMG—VCU; Sharon Williams, MS, RN—VDH; Theresa Taylor—VDH; Virginia K. Proud, MD—CHKD; William G. Wilson, MD—UVA Health Sciences Center; Willie Andrews—DCLS

**Absent:** Alice Schreiber, MS—VDH/VCU; Allison Schroeder—Parent; Anil Kuma; MD—VCU; Arti Pandya, MD, MBA—VCU; Bonny Bukaveckas, PhD—VCU; Cliff Schroeder—Parent; David Suttle, MD—VDH; Gwen Smith, RN, MSN—VDOE; Heather Trammell—Parent; James Pearson, DrPH, BCLD—DCLS; Jana Monaco—Parent; Jene Radcliffe-Shipman—VDH; Joan Corder-Mabe, RNC, MS, OGNP—VDH; Joanne Boise, MSPH—VDH; Mary Ann Discenza—DMHMRSAS; Paula Miller—Parent; Ramona Schaeffer—VDH; Susan Ward, VP—VHHA; Valerie Luther, VDPPPD; Vicki Hardy-Murrell, RN—Parent; Walter Nance, MD, PhD—VEHDIP Adv Cmt.

**Recorder:** Rafael Randolph

1. **Welcome: J. Bodurtha**
  - a. Introductions: Completed.
  - b. Draft minutes of 04/04/06: Brooke Mercedes is not the new genetic counselor at EVMS. Minutes approved with correction. Final minutes will be posted on the VDH Minutes Calendar Web site <http://www.vdh.state.va.us/minutes/minutes.asp> and the Virginia Regulatory Town Hall Web site <http://www.townhall.virginia.gov/intro.cfm>.
  - c. Agenda: Reviewed, no new items added.
  - d. Membership (revised 10/03/06): Circulated for corrections. Plan:  
☐ N. Ford will update and email to VaGAC.
2. **Virginia Project for Children and Youth with Dual Sensory Impairments/Deaf-Blindness: M. Campano**

A presentation on the project, along with project literature, was provided. Highlights:

  - Census Data:
    - The National Technical Assistance Consortium (NTAC) December 1, 2004, census count reported that 8,999 individuals between the ages of 3 to 21 have deaf-blindness; however, the federal census count (state DOE counts) showed only 1,977 students with deaf-blindness.
    - In 1999, the Deaf-blind International reported that 85% of the total deaf-blind population has additional impairments and disabilities.
    - The NTAC December 1, 2004, census count reported that 63% of these individuals had cognitive impairments, 56% had physical disabilities, 38% had complex health care needs,

and 9% had behavioral disorder (behavioral issues are typically a misinterpretation of communicative needs being acted out physically).

- **Project Services:**
  - Provide information, which includes a lending library of books and videotapes regarding deaf-blindness and referral to additional services, training, or resources for materials and equipment.
  - Provide assistance and consultation, which includes parent-to-parent support via meetings, focus groups, phone, e-mail and listserves, and consultation to families, school districts, and other educational agencies in the home, at school, to IEP and IFSP meetings, via phone, e-mail, and interactive videoconferencing.
  - Provide trainings, conferences, and workshops for professionals and families on a variety of topics, which may include awareness of impact of deaf-blindness, assessment, communication, behavior, educational programming, transition, social/emotional development, assistive technology, resources, and curriculum development.
- The project also emphasizes the importance of communication, functional visual assessment, and family. Family is a very important element for many of the children with deaf-blindness because it is usually the only thing that stays constant in their lives.
- **Marketing Program:** Several contact recommendations were provided by VaGAC, including school nurses via G. Smith, DOE, and S. Schrader, VDH, and Care Connection for Children Coordinators via N. Bullock, VDH.
- Additional project information is online at <http://www.twc-deafblind.state.va.us/index.html>.

### 3. **VaGAC Infrastructure: J. Bodurtha**

The Infrastructure document was reviewed and updated. Plan:

- ☐ VaGAC Steering Committee will address how to look at issues globally using a different perspective (e.g., parents, consumers, and self-advocates).
- ☐ VaGAC Subcommittee Chairs will send membership updates to N. Ford.
- ☐ VaGAC Members will notify N. Ford if interested in joining a subcommittee.
- ☐ N. Ford will make the following changes on the Infrastructure document and send to VaGAC:
  - Change “State Genetics Plan Work Group” to “State Genetics Education Plan Work Group.”
  - Delete “Tandem Mass Spectrometry (MS/MS) Work Group.”
  - Update subcommittee members lists.

### 4. **Subcommittees and Work Groups Reports**

#### a. **Genetics and Public Health Subcommittee: J. Bodurtha**

The State Genetics Education Plan Work Group is currently working on developing a state genetics education plan based on results of the March of Dimes-funded 3-year genetics needs assessment. At the last meeting, 36 different agencies attended. The following outreach activities have been conducted: (1) Broad Rock Library—presentation was conducted by J. Bodurtha, H. Creswick, A. Westerberg, and a VCU student intern on the family health history to a mostly Latino population, who indicated that Latino families were interested in their family health history but did not have an opportunity to talk about it until this forum; (2) Chesterfield Health Fair—a display board that included the following topics was developed by H. Creswick and set up at the fair but was not staffed: Careers in Genetics, Secrets of the Sequence, State Genetics Education Plan, and Family Health History; and (3) Stony Point Library—a family health history workshop was conducted. The Subcommittee is soliciting volunteers to help at upcoming family health history workshops. The next Subcommittee meeting is October 18, 2006, at the March of Dimes Office.

#### b. **Newborn Screening Subcommittee: L. Bartlett /W. Andrews**

The Subcommittee met in April 2006. Expanded newborn screenings began March 1, 2006.

Since that time, 70,000 samples have been collected and 41 individuals were diagnosed with one of the new disorders. DCLS hired a PhD lead scientist, Phillip Posten. The topic of how/who should answer questions from metabolic centers to the Subcommittee was raised. Plan:

- ☐ W. Andrews will develop a communication plan (e.g., protocol) for responding to questions put forth to the Subcommittee.

c. **Community Partnerships Subcommittee: Parent Involvement Work Group: N. Ford (for A. Schreiber):**

The Subcommittee helped VaCARES achieve a significant goal: the reinitiation of VaCARES parent contact, which includes mailing a parent letter, parent brochure, and fact sheet. The Subcommittee reviewed a version of the parent letter that had been sent in the past and offered very helpful feedback, including improvements in wording and content. After the letter was revised, the Subcommittee reviewed it again and approved the letter. The first group of letters was mailed in August 2006.

d. **VDH Contractors Subcommittee: S. Williams**

The Subcommittee had a teleconference in July 2006, and a teleconference was conducted with the metabolic centers Registered Dietitians. A Subcommittee meeting will be convened today following the VaGAC meeting and will include reviewing and revising the quarterly reports.

5. **Updates: Agencies, Organizations, Grants**

a. **VDH: PSGS Grants VaCATPIP II, VaCHISIP: N. Ford**

The CDC-funded birth defects surveillance and evaluation grant (VaCATPIP II, Year 3) is due October 20, 2006. As mentioned before, VaCARES parent contact was reinitiated. A lot of new folic acid materials have been published and made available to health districts. New PSAs have been developed and will be broadcast pending available carryover funds. The materials and PSAs are available on the newly redesigned Virginia Folic Acid Campaign Web site <http://www.vahealth.org/folicacid/>. The CDC-funded Early Hearing Detection and Intervention grant (VaCHISIP) VISITS redesign activities have recently focused on linking VISITS with Electronic Birth Certificates, which should limit duplicates and improve data quality. A statistical analysis was hired who is working on future VaCARES reports, which will include a five-year (1999-2003) trend report and annual reports beginning with 2004 data.

b. **VDH: Virginia Sickle Cell Awareness Program: J. Bodurtha for J. Shipman**

VCU Medical Center hosted a one-day event on September 29, 2006, which showcased a variety of clinical and basic science research relevant to sickle cell disease being done at VCUMC. J. Radcliffe-Shipman has been invited by the International Hospital for Children to attend a Sickle Cell Focus Conference at the La Romana Hospital in the Dominican Republic, October 14-18, 2006. The Sickle Cell Child Health Passport has been completed and was circulated. Through a VDH press release on September 22, 2006, VDH highlighted accomplishments in educating school nurses through its new publication "Understanding Sickle Cell Disease: A Handout for School Personnel." The 30-page booklet provides a brief background on the disease, its physical complications, and its warning signs. It also provides school personnel with specific steps they can take to care for the approximately 800 children with sickle cell disease who are enrolled in Virginia schools. The press release is online at <http://www.vdh.state.va.us/news/PressReleases.asp>. The publication is online at <http://www.vahealth.org/sicklecell/pubssc.htm>. Governor Kaine declared September as Sickle Cell Awareness Month. The 2006 Nobel Prize for Medicine will be shared by Stanford's Andrew Fire and the University of Massachusetts Craig Mello for their detective work on the phenomenon of RNA interference (RNAi), which has the potential to revolutionize medicine. Information about the award is online at [http://www.theregister.co.uk/2006/10/02/nobel\\_medicine\\_2006/](http://www.theregister.co.uk/2006/10/02/nobel_medicine_2006/).

c. **DCLS: W. Andrews**

DCLS and VDH have been working with Save Babies Through Screening Foundation, Inc. to

update their Web site information on Virginia, and as a result of this work, the national genetic site was contacted and informed that its online Virginia data are inaccurate.

d. **March of Dimes and Va. Council on Folic Acid: S. Long**

The 2006 Prematurity Initiative Conference for health care professionals, researchers, graduate and medical students, and families will be held on November 10, 2006, in Richmond. The focus is on issues related to premature birth. Topics will include the NICU Experience, Neonatal Ethics, A Premature Infant's 1st Year, and Preventing Premature Birth. Welcoming remarks will be provided by Governor Kaine. The conference is sponsored by the March of Dimes Virginia Chapter and the Family Support and Research Center, Department of Psychology Center for Psychological Services and Development, Virginia Commonwealth University. More information is online at [http://www.marchofdimes.com/virginia/9902\\_21438.asp](http://www.marchofdimes.com/virginia/9902_21438.asp).

e. **DMHMRSAS: Part C of IDEA: Infant & Toddler Connection of Virginia: M. A Discenza**  
No report.

f. **VDH: Children with Special Health Care Needs Program: N. Bullock**

As of March 1, 2006, all individuals who are diagnosed through Virginia Newborn Screening Services are referred to the Care Connection for Children (CCC) Program. So far, 44 referrals have been received. CCC Pool of Funds supports the provision of certain metabolic formulas to eligible individuals as a part of the VDH Formula Distribution and Purchase Plan. The following is a summary of the VDH Formula Distribution and Purchase Plan and VDH Food/Supplement Reimbursement Plan:

- Formula Distribution and Purchase Plan: Provides certain metabolic formulas, or mechanisms to purchase these metabolic formulas, to Virginia residents who meet the financial and medical eligible criteria.
- Food /Supplement Reimbursement Plan: Provides limited reimbursement for certain low protein modified foods and/or metabolic supplements to Virginia residents who meet the financial and medical eligibility criteria.

g. **DOE: G. Smith**

No report.

6. **Updates: Virginia Genetics and Metabolic Centers**

a. **EVMS: V. Proud**

Teresa Meadows and Kara Thomas were reintroduced. New referrals increased from 500 to 900. EVMS is currently recruiting for a geneticist.

b. **UVA: B. Wilson**

The recent academic appointment of Stephen Braddock, M.D., Professor of Clinical Pediatrics, Department of Pediatrics, Division of Genetics, University of Virginia Health System, was announced. S. Braddock's previous academic appointment was at the University of Missouri, and he has special interest and experience in Fetal Alcohol Syndrome Disorders. A presentation by S. Braddock at a future VaGAC meeting was suggested. Concerns related to recent problems involving Virginia Medicaid law on out-of-state testing (e.g., testing laboratories cannot bill hospitals directly) were raised. Solution would most likely involve changes in legislation. Perhaps March of Dimes would consider becoming involved with this issue.

c. **VCU: J. Bodurtha**

There is a noticeable increase in the volume of newborn screening activities. An article on family history was recently published in the *Richmond Times Dispatch*.

*Draft*

**7. New Business: All**

- The March of Dimes is developing its public affairs plan for 2007. It will focus on two issues.  
Plan:  
☐ VaGAC Members will e-mail suggestions to S. Long at [slong@marchofdimes.com](mailto:slong@marchofdimes.com).

**8. Next Meeting: J. Bodurtha**

- a. Virginia Genetics Advisory Committee Meeting:  
Date: Tuesday, April 17, 2007  
Time: 10:00 a.m.-12:00 p.m.  
Location: Division of Consolidated Laboratory Services
- b. VaGAC Steering Committee Conference Call  
Date: Thursday, March 8, 2007  
Time: 3:00 p.m.

**9. Adjourn: J. Bodurtha**

Meeting adjourned at 12:03p.m.